# Donate





Missouri Organ and Tissue Donation

2012 Annual Report

**Governor's Organ Donation Advisory Committee** 





Missouri Organ and Tissue Donation 2012 Annual Report

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#### Organ and Tissue Donor Program MISSION

living donation.

Volunteer Efforts

Four volunteers are getting the word out about organ and tissue donation.

Close the gap between the need and availability of organs and tissues through informed citizens and an efficient, confidential registry of potential donors.



Peter Nicastro

#### From the CHAIR PER SON

If I had a single word to represent the focus of the Organ and Tissue Donor Program in the past year, it would be gratitude. First and foremost, I'm grateful to you, my fellow Missouri citizens. Recently, we surpassed three million Missourians registered in the Donor Registry System, and are quickly approaching 50 percent of the state's approximately six million population. That's an exceptional number! Just this year, more than 148,000 individuals were added to the registry. At the same time, you were very generous, even in these difficult economic times, in donating to the fund that supports registry operations. Donations increased to \$308,000. Many Missourians took advantage of the new opportunity to contribute on their individual income tax returns. Contributors should consult their tax advisor about the potential deductibility of any contribution.

I'm also thankful for the engagement and participation of the Department of Revenue (DOR) and the local license offices. The vast majority of registrations and donations come through license offices, and therefore the program is very dependent on the hard work these offices do every day. Last year we began recognizing license offices quarterly. License offices with the highest registration and donation rate received a certificate from a committee member or one of our partner agencies. These leaders are recognized in a DOR

publication distributed to all the license offices, and the DOR raised awareness by including organ and tissue donation updates in their weekly messages. This year we began identifying the most improved offices to highlight those offices working hard to be organ and tissue donor friendly.

In addition, I appreciate the hard work of our agency partners, including Mid-America Transplant Services (MTS), Midwest Transplant Network (MTN), and the Heartland Lions Eye Bank (HLEB). Beyond their participation on and with the advisory committee, these agencies work in their respective communities to raise awareness of the need for donor and tissue designation. For example, MTS analyzed data provided by the Donor Registry System to identify zip codes in their service area where registration rates were low, and are reaching out to license offices in those communities to help educate staff and patrons on the importance of donor designation and dispel misconceptions.

Finally, I'm grateful to the program staff and the leaders at the Department of Health and Senior Services (DHSS), who do the day-to-day work of answering questions; processing registrations, removals and deaths; and creating reports to update everyone on the progress I mentioned.

Thank you!

Peter Nicastro, Chairperson, Governor's Organ Donation Advisory Committee



**Margaret Donnelly** 

From the DIRECTOR

ife is about making decisions. Some decisions are made at the last minute or when it's too late. Joining Missouri's Organ and Tissue Donor Registry is a personal decision that can be made right now because it is a first-person consent registry. Previously, a family member had to make the final decision for organ and tissue donation at the time of death. The registry eliminates any doubt that a family member may have about a donor's decision.

Almost every day a donor saves the lives of up to eight people and enhances the lives of at least 50 others. Then there are living donors, like Lee Summers, who donated a kidney to her father. Ms. Summers volunteers for Gift of Life through the Life Mentors program, giving encouragement and support to those waiting for a transplant.

I'd like to commend Peter Nicastro, chairperson of the Governor's Organ Donation Advisory Committee (GODAC), for his outstanding leadership, and extend my appreciation to all members of the committee. The 2012 annual report reflects the progress Missourians have made in helping the thousands of people on the transplant waiting list. I invite everyone to visit the registry website to register or update their profile at www.health.mo.gov/organdonor.

Sincerely,

Margaret Donnelly, Director, Missouri Department of Health and Senior Services

## ADVISORY COMMITTEE



Jan Finn

The GODAC is a 10-member group that develops organ donor awareness programs to educate the public about the importance of organ donation. The group consists of four representatives from organ procurement agencies, four organ recipients, organ donors or family members of organ donors, one health care representative and one representative from the DHSS. One member was reappointed to the committee in 2012.

Jan Finn was reappointed to the committee on March 21, 2012, representing the organ procurement organization, Midwest Transplant Network. As chief operations officer, Jan has provided executive leadership to a team of more than 100 full time staff since 1998, which resulted in increased organ transplantation by 72 percent in three years and increased organ donation rates from 65 percent in 2003 to 84 percent in 2010. In addition, Ms. Finn was recruited to serve as the National Improvement Leader for the Health Resources Services Administration (HRSA) Breakthrough Collaborative. Ms. Finn is an outstanding organizational media spokesperson and is responsible for the MTN communications center, which fields 25,000 referral calls annually.

"Our work is aimed at providing hope to those who wait for the precious gift of life with a transplant and educating Missourians about their ability to save lives."

"It is my pleasure to be reappointed to the GODAC."

ridging lives between organ and tissue donors with recipients is of utmost importance to both donor families and transplant recipients."

– Jan Finn, Organ Donation Advisory Committee Member

#### **Governor's Organ Donation Advisory Committee**

#### **Donor or Recipient Family Representatives**

Debbie Simaitis, donor family Harry K. Ratliff, recipient family

Phil Duncan, heart recipient

Peter Nicastro, double lung and kidney recipient

#### **Hospital Representative**

Joan Keiser, Chaplain, Mercy Hospital Springfield

#### **Procurement Agency Representatives**

Jan Finn, Midwest Transplant Network
Heidi Hernandez, Midwest Transplant Network
Ronald Walkenbach, Ph.D., Heartland Lions
Eye Banks and cornea recipient

Vacancy

#### Department of Health and Senior Services Representative

Virginia Beatty, Organ and Tissue Donor Program

## COMMITTEE REPORT

The members of the GODAC continue in our dedication to raising public awareness of the need for organ, tissue and eye donation, both individually and collectively, to all corners of the Show-Me State.

The committee met three times: September 2011, January 2012 and May 2012. The bulk of our September meeting was an orientation to the Committee for the many new members who joined in 2011, and a refresher for veteran members. Members and stakeholders heard from several employees of the DHSS, including Department Director Margaret Donnelly, Program Director Virginia Beatty and Division Director Harold Kirbey, who presented the history of the committee, the current statutory authorization and the revised Uniform Anatomical Gift Act, the program's funding and budget, and how the registry operates. The orientation answered many questions and raised others, resulting in the formation of a new team to reconsider the committee's and the program's strategic plan, goals and initiatives, to be refined over the next year.

Committee members participated corporately in two key events, along with many stakeholders supporting organ, tissue and eye donation, related to the celebration of National Donate Life Month in April. On March 22, Gov. Jay Nixon graciously welcomed everyone to his oval office, to sign the proclamation declaring April to be Donate Life Month in Missouri. By inviting us in March, the Governor assisted with a plan to have his proclamation and photos from the signing available to all our partners throughout the entire month of April for use in awareness building activities. On April 17, everyone was back at the Capitol to join in an annual Donation Awareness Day. Supporters were in the Capitol Rotunda speaking to those who stopped to ask questions about donation, registering those who wished to join the registry live using the online registry website, and raising interest and traffic by distributing donation-themed frosted cookies, which came packaged with a reminder to register and the website URL.

In October 2011, Peter Nicastro, Deb Simaitis and Phil Duncan attended training in Jefferson City directed at all the state boards and commissions, about the general responsibilities of board members, the state budgeting process, and the requirements of the state Sunshine Law. Following the highly informative training, their families joined them for a reception at the Governor's Mansion with the Governor and First Lady.

Members also engaged their communities during other parts of the year and at other events. For example, Deb Simaitis, whose husband Sandy is chairman of their local fire board, spoke to that local department about how emergency responders can help facilitate donation; and joined Kansas City based Gift of Life to bring their program

to rural high schools farther from Kansas City. Harry Ratliff continues to focus on expanding Minority Donor Day, which is August 1, by connecting Christian Hospital in St. Louis with the MTS. Many members assisted in distributing the recognition certificates to local license offices, providing a personal touch to this initiative.

#### **Summary of Committee Activities**

	Registry Drives	Awareness Events	Organization Webpage Updates	Facebook Postings	Collaborative Meetings (State and National)	School Education	News- letters (electronic and paper)	Hospital Staf and Other Professional Education
Ron Walkenbach	3	7*	10	0	3	0	3	0
Joan Keiser	0	3*	0	0	0			26
Deb Simaitis	0	15*	NA	0	1	1		1
Peter Nicastro	0	2*	0	12	1			
Heidi Hernandez	2	4	0	0	10	0	0	4
Virginia Beatty	0	2*	2	4	1	0	2	0
Jan Finn	0	8	0	45	10	0	3	12
Harry Ratliff	0	0	0	0	0	0	0	0
Phil Duncan	2	10*	0	3	6	18 Hours, 90 Classes and 2,000 Students		0

<sup>\*</sup> Donate Life Month Proclamation Signing and Donate Life Month Awareness Activity at the State Capitol Rotunda (2 activities)

## EDUCATIONAL INITIATIVES

#### Department of Health and Senior Services

The DHSS participated in several educational initiatives during fiscal year 2012, including registry drives, health fairs, an information booth for local public health administrators, Capitol Awareness Day, Flaunt Your Blue and Green, articles in the employee newsletter and responding to public inquiries, etc.

Flaunt Your Blue and Green was part of the 20 Million in 2012 Campaign designed by Donate Life America. The department invited all DHSS employees to assemble their best blue and green business attire and wear it to the office on Friday, April 20, 2012. Groups that participated had an opportunity to post their photo on Donate Life Missouri's Facebook page. Employees were encouraged to take a few minutes to learn about organ and tissue donation, and if the decision was to be an organ, eye and tissue donor, to register that decision. The effort was so successful nationally that it may become an annual event.

The DHSS staff continue to collaborate with Team Missouri, organ procurement organizations, DOR, Missouri Hospital Association, Missouri Kidney Program (MoKP), and others to help educate the public about organ and tissue donation, registering decisions and informing family members of decisions.

In addition, the DHSS became part of a cross-departmental work team that assures program efforts are compliant with the law, assures registry enrollment processes are effortless, and examines how to expand public educational efforts.

For more information about the Missouri Organ and Tissue Donor Program, visit www.health.mo.gov/organdonor.



#### **Department of Revenue**

The DOR sent out five issues of their electronic license office newsletter during state fiscal year 2012 that contained information about organ and tissue donation. The newsletter is sent throughout the state. Article topics included:

January 13, 2012 – The January issue of the newsletter addressed four common myths. Myths addressed were: Having cancer will keep me from being a donor; organ and tissue donation will disfigure the body; my family will be charged if I donate my organs; and no one wants my organs and tissues because of medical history. The link to the organ donor registry website was added.

February 17, 2012 – A series of facts about Missouri's Organ and Tissue Donor Registry System began with this issue. The questions asked and answered in the newsletter were: Who manages Missouri's Organ and Tissue Donor Registry and what happens when I enroll in Missouri's Organ and Tissue Donor Registry?

March 2, 2012 – The second in the series of facts addressed the following questions: How do I make changes to my registration and can I specify or change my donor preferences?

March 16, 2012 – The third in the series of facts about Missouri's Organ and Tissue Donor Registry System addressed: May I later withdraw or revoke my consent to be listed in the organ and tissue donor registry and how can I remove my name from the registry?

April 6, 2012 – This particular issue highlighted successful license offices with the highest percentage of registered donors for their transactions. Offices highlighted were Lee's Summit (55 percent), Des Peres (55 percent), Liberty (54 percent) and Ozark (54 percent).

#### **Heartland Lions Eye Banks**

During fiscal year 2012, the HLEB conducted nine registry drives, participated in 21 awareness events, posted updates related to tissue donation daily on their webpage, attended several collaborative and advisory committee meetings, and published fifteen newsletters. In addition, they participated in two high school education programs.

One such awareness event was Mr. David Landsberg's (kidney transplant recipient) ride around the country to save lives; Donor's Rock' Ride: 50 states, 50 days, 50 rides. In Missouri, riders gathered on August 1, 2011 in Columbia, Missouri. The national event was a unique way to spread the message about increasing donor designations throughout the United States. The HLEB organized an event in Columbia, Missouri where Mr. Landsberg could share his message and riders could join him for a day of cycling. You can read more about Mr. Landsberg at http://blog.midmotoday.com/columbia-missouris-donors-rock-ride-august-1-2011.

The HLEB also chairs the Donate Life Missouri team. A team of partners dedicated to educating the public about organ and tissue donation and to increasing donor designations in Missouri's registry. They help administer the Donate Life Missouri website (7,500 unique visitors), Facebook (255 followers) and Twitter (219 followers) accounts.

For more information about the HLEB, visit www.hleb.org.

#### Mid-America Transplant Services

The MTS engaged more than 4,000 students during the 2011-2012 school year through its on-site student education program designed to teach high school students about the organ and tissue donation process. The program provides free bus transportation to the MTS facility for participating schools within St. Louis, Mo., St. Louis County and surrounding areas.

For the 2011-2012 school year, MTS introduced a Teacher Resource Guide, which provides teachers a 30-page, interactive PDF with information, videos, and available online resources to further engage students. During the 2012-2013 school year, MTS will focus on schools in areas where the designation rate is low. MTS will continue its partnership with Saint Louis University's Adventures in Medicine and Science program, in which students handle real human organs.

During the on-site, highly interactive presentations, students are given information about organs and tissues that can be donated, who is eligible for donation, and how organs are allocated. Students also discuss the role of MTS, the need for organ and tissue donation and how to sign up to be an organ and tissue donor. The most important topic addressed is about talking with his or her family about organ and tissue donation and the wishes of each family member. The program often includes a trained volunteer sharing his or her story and helping with activities.

The presentation concludes with a tour of the facility, including the operating room, intensive care unit, Eye Bank, the Communications Center and AlloSource, a partner with MTS that responsibly develops, processes and distributes live-saving and life-enhancing human tissue.

Contact T'Shon Young, MTS education coordinator, at 314-735-8456 for more information.

#### Missouri Kidney Program

The MoKP is proud to partner with the Missouri Organ and Tissue Donation Program and to be an ad hoc member of the GODAC. The MoKP represents all Missourians with Chronic Kidney Disease (CKD). It is estimated that 1 in 9 Missourians are at risk of CKD due to our state's high rate of diabetes, hypertension, obesity, and an aging population. The MoKP offers free educational classes for these citizens as their kidneys start to fail. These classes focus on prevention and delaying the progression of end-stage kidney disease or CKD Stage 5. It also explains the treatment options of hemodialysis (in-center and home), peritoneal dialysis, and transplantation (deceased donation and living donation). The best medical treatment option available to kidney patients is to have a kidney transplant from a living donor before the start of dialysis. Our classes provide patients and families with this "best practice" information, including steps to be a transplant candidate, and ways to find a suitable living donor within your network of family, friends and community.

The MoKP also has a direct assistance program for low-income CKD Stage 5 patients to help with medications. Transplant medications are essential, but can be very expensive. Many patients may not consider a transplant due to the medication expense. The MoKP steps up to help these patients with the costs of medications, until the patient can obtain other coverage.

The MoKP advocates on behalf of the approximate 10,520 Missouri CKD Stage 5 kidney patients; 1,094 of which are waiting for a kidney transplant. We host a yearly Kidney Awareness Day at the Capitol in March with exhibits and visits with legislators. During fiscal year 2012, MoKP actively engaged with the MO HealthNet officials, explaining the impact that recent Spend Down changes will have on patients as they access their dialysis or transplant care. Our mission is to represent kidney patients' needs and concerns.

For further information on the Missouri Kidney Program, please call 800-733-7345 or visit http://som.missouri.edu/mokp.

#### **Midwest Transplant Network**

The MTN hosted its annual donor picnic on August 25. The event unites hundreds of donor families and ambassadors to celebrate those who have given the gift of life.

The MTN hosted their Celebration of Hero's service November 10 during National Donor Sabbath to honor organ and tissue donors, an annual event for more than 20 years. Additionally, MTN will continue with the National Donor Sabbath program with relationships that have been built by last year's clergy symposium, Links, the last two years' participants, Ambassadors, donor families and top 20 (in membership) places of worship with-in the service area.

The Work Place Partner program had another successful year by adding additional work-place partners and implementing a Work Place Partner Hospital campaign resulting in 27 large hospitals signing up.

Through MTN's Donor Designation Coordinator Sarah Jane Dolezal, MTN has visited 75 out of the 85 local driver license offices at least once for an educational presentation. Eight of those offices have been visited twice and nine of the 75 have been visited three times; this includes watching the MTN "Gift of Life" video and listening to an Ambassador share his or her story.

Staff and volunteer members have reached more than 12,000 students through educational programs conducted at nursing schools, licensed practical nursing programs, colleges, high schools and middle schools.

Brooke Connell joined the team as public relations and marketing specialist in May. She leads MTN's social media presence on Facebook, Twitter and You Tube, as well as coordinating media and marketing efforts.

The MTN worked with University Hospital in Columbia, Mo., for the 2012 Missouri State Fair that produced tremendous amounts of interaction with the public about the Missouri Organ and Tissue Donor Registry.

Throughout the year, MTN hospital services have provided symposiums for Emergency Department, Intensive Care, Operation Room and Palliative Care staff along with a collaborative trauma conference with Truman Medical Center.

In August 2011, the MTN partnerered with Boys & Girls Clubs of Greater Kansas City to host a Minority Donor Awareness Day. The organizations educated the local community about the facts and importance of organ and tissue donation. Information for adults and youth was available. A registry drive was also held.



Lee was an organ donor for her father and became an example for others.

## ONE GIFT MONE TO THE STATE OF THE STATE OF



"Present" is the adjective to describe Lee Summers. She pays attention to those around her and cares about their well-being. As a Pilate's instructor in Kansas City, it may be second nature to her. But Lee is also this way because she understands the value of altruism – giving the gift of self to encourage and support those around you.

Lee Summers and her father, Gary Summers, and dog, Jack Henry

#### by Keith Anderson Gift of Life

he gave this gift of self to her entire family when she became a living kidney donor to her father. Gary Summers lives in Springfield, Mo., and came to Kansas City for a transplant on December 1, 2009. With over 110,000 individuals on the national waiting list, Gary wondered how long his wait would last. Through testing, the family learned that Lee's sisters and her mother were also matches. In cases like this, the hospital social workers work with the family toward a successful transplant and recovery examining best options for all parties. Lee was determined to be the best candidate within her family. She had the career flexibility and was in excellent physical condition. But there are other reasons she agreed to be a living donor to her father – more than just the physical match. She had the desire to help her father and others.

The backbone of her decision was altruism in its purist form. Lee knew that her father could wait for an anonymous donation, and for many parents that might be their preference. She also knew that other family members were a match, so why her? After weighing the options, Lee stepped up to the plate. Her father could wait for months to years waiting for an anonymous donation. She also understood that an anonymous or deceased donor could save another life if she became the donor to her father – not to mention standing in the place of her mother or sisters.

All of this comes back to the spirit of Lee being "present" and listening as they discussed her father's condition. Ultimately her actions saved her father and one other person, helped two families, helped her sister's families and gave another donor family the opportunity to make a difference as a legacy to their loved one.

Lee chose to pay it forward, but her story doesn't end there. She has continued to make a difference by sharing her story and moving forward as a volunteer Life Mentor for Gift of Life, a Kansas City nonprofit. Life Mentors offer encouragement and support to those waiting for a transplant, new recipients, donor families and living donors. In Lee's case, she has drawn upon her experience as a living kidney donor to answer question and assist other families facing this decision. Ironically, she has worked with another young woman in the same situation who works for a local advertising agency. Lee was able to visit with her and her father, listen to their questions and help them understand how one living donor can change multiple lives.

Many would make that same decision, but Lee saw this as a way to participate in the altruistic community shining light on a path for others who might give living donation the same consideration. The donor registry continues to grow in Missouri and many waiting for a life-saving transplant are not blessed with a living donor option. Lee and her family know the value of the gift. They believe if their act of living donation enables another person on the list to receive the gift of life...then they will have made a difference to their family plus another family and many more.



#### New heart provides second chance

by Justin Phelps, Mid-America Transplant Services

Before Chase Reid was born, his mother Na'Tasha knew her little boy had a long road ahead. But after many surgeries, a new heart gave Chase the Gift of Life and a second chance. At 24 weeks gestation, Chase was diagnosed with Tricuspid Atresia, a heart defect present at birth in which one of the valves does not form between the two chambers in the heart.



fter the transplant, he has no limits. He has a full range of activities like every other child."

- Na'Tasha Reid

Chase's surgeries began at 8 days old. He had five heart procedures and was added to the transplant list in January of 2010. Five months later, on June 17, 2010, his family received a call about his new heart. "Transplant has changed our lives tremendously, because without it, Chase would not be here today," Na'Tasha says.



Chase had a setback two months after he received his transplant when he suffered from a bleed on the brain, also known as a wet stroke. He shows signs of residual side effects from the stroke with slight paralysis on the right side of his face and limited usage of his right arm and hand. "Because of his year-long stay in the hospital, Chase is not yet walking or crawling," Na'Tasha says. "Nonetheless, he is a thriving 2-year-old child."

Chase enjoys music and therapy sessions. He went to the zoo recently and especially liked the penguins. "Without a transplant, he would have been very limited with outdoor activities," Na'Tasha says. "After the transplant, he has no limits. He has a full range of activities like every other child."

Today, Na'Tasha volunteers for Mid-America Transplant Services with Chase in spreading the message of organ and tissue donation. In 2012, they attended several registry drives, school presentations, church presentations, spoke with KSDK-TV for a live on-air interview, and Na'Tasha addressed the crowd at the Missouri Black Expo in St. Louis in August.

"Na'Tasha is a highly engaged and dedicated advocate of organ and tissue donation," said Christie Judd, MTS's Community Relations Coordinator. "Her gratitude for what Chase received endures. She hasn't forgotten the gift he received, and she lives every day remembering. When she's called upon, she's always excited to share the message. She's amazing."

Chase and Na'Tasha Reid



#### Cornea recipient shares his story

by Nicole Plegge, Heartland Lions Eye Banks

Prior to receiving his cornea transplant, Mike Foley saw everything around him in a blur. He had never been able to enjoy the beauty of the stars in the sky or Christmas lights during the holiday season. However, the joy of seeing Christmas lights for the first time with his family after he received his transplant was truly an incredible experience. And that's what Mike has been able to do so much more of since his surgery – experience new things thanks to receiving the gift of sight from a generous donor family.

Mike developed keratoconus, a condition in which the cornea becomes cone-shaped and the vision becomes impaired, during adolescence. By the age of 24, his vision became so bad it affected his ability to work and to enjoy his favorite activities – a transplant was the only option to restore his vision.



Mike Foley

Prior to surgery, Mike's vision in his left eye was 20/220; soon after his transplant, his vision drastically improved to 20/40. With his restored sight, Mike was able to get off welfare and secure a career that allowed him the freedom to financially support himself for the first time in his life.

Mike feels a special connection to the donor family and the people who have worked to help make his transplant possible. For Mike, his true heroes are the donors and donor families who made the decision to share sight and life with others. Since his transplant, Mike has been one of Heartland Lions Eye Banks' most active volunteers, encouraging Missourians to register as eye, organ and tissue donors. He speaks about his journey regularly at Celebrations of Life, Lions Club meetings, and other community events. He also served as a recipient spokesperson for the Eye Bank's media campaign in conjunction with the annual Donate Life America Rose Parade Float. In 2011, Mike was the face for the Eye Bank's holiday appeal fundraising efforts.

Every day, Mike is reminded of the gift he has received and gives thanks for the chance to finally see the world around him. The stars that he put on the ceiling in his house remind him how truly wonderful it is to be able to see life's small beauties again.

ikes' true heros are the donors and donor families who made the decision to share sight and life with others.

## VOLUNTEERS

#### Donor mom reaches thousands

by Ray Gabel, Midwest Transplant Network



Connie Koch

When a person or an organization defines the "ideal" Ambassador or volunteer it should be based on a person like Connie Koch. She is outgoing, full of energy and incredibly dedicated.

Connie's story goes back to 1998 when her youngest son, Jesse Harrison, passed away at the age of 17 in a car accident on Fourth of July weekend. When she found out he would not survive, she asked that his organs be donated. She did not know at that time that Jesse had already filled out an organ donor card. "To be a donor mom, unfortunately, you have to have lost a child; he saved and enhanced the lives of more than 60 people, so that makes Jesse my little hero," said Connie.

Connie has taken what would be hard for any mom to deal with, and turned it into a mission to help others understand the importance of organ and tissue donation. With close to 14 years as an Ambassador for the Midwest Transplant Network, she has definitely made a difference.

She has given countless speeches at health fairs and community outreach events. As the former director of the United States Air Force community center at Whiteman Air Force Base, she ensures that every service person understands the importance of organ and tissue donation.

In 2004, a group of cyclists, called the Five Points of Life Riders, whose mission is to promote organ, tissue, blood, plasma and bone marrow donation, came through Knob Noster, Mo., the home of Whiteman Air Force Base. Connie jumped at the chance to help out. She arranged for these dedicated riders and crew to stay on base and to get a rare opportunity to sit in a stealth B-2 bomber. Connie was so moved by these committed individuals that she chose to join the group in 2006. She rode 3,000 miles with the team, which traveled from Ottawa, Canada to Miami (South Beach), Fla., continuing the legacy of her son, Jesse.

In 2012, Connie met Jesse's heart recipient, John Frieling, and his wife Margaret. Connie and Margaret volunteered at the 2012 Missouri State Fair to promote the importance of organ and tissue donation. Unfortunately, John has since passed, but Connie and Margaret remain friends and Midwest Transplant Network Ambassadors.

to be a donor mom, unfortunately, you have to have lost a child; he saved and enhanced the lives of more than 60 people so that makes Jesse my little hero."

-Connie Koch



#### Back in the game!

by Keith Anderson, Gift of Life

"I wanted to pick out my wedding dress before I lost my sight so I could picture myself on my wedding day." This is the optimism and can-do spirit that Lisa Zimmerer of Kansas City, Mo., exudes as a volunteer speaker for Gift of Life. Selected as the organization's volunteer of the year, she engages students with the details of a journey that includes a life-saving transplant and losing her sight along the way. Life dealt her a shuffled deck and now using braille cards, she uses those same cards to beat friends and family in poker.

he is back in the game! If anyone can inspire young people deciding to register as organ donors, that person is Lisa Arthur Zimmerer.

The transplant chapter of her story begins in 2006 with the diagnosis of both kidney failure and diabetic retinopathy, complications of the diabetes she had struggled with since age eight. Her health was failing and she knew that her eyesight would soon fade. Fortunately, she had the support of her fiancé, Bob Zimmerer, parents Willene and Lawrie Arthur, and three aunts known to her care team as her "Mother Hens." Lisa endured four hours a day on hemo dialysis at home and waited for over a year to receive a kidney/pancreas transplant.

Lisa received the gift of life on September 3, 2008, through The Transplant Institute at Research Medical Center and thanks to a family that made the decision to donate the organs of a loved one. That day was the end of daily insulin shots, daily dialysis, and the anxious wait that is so familiar to many in need. Lisa had a new life, a new wedding dress and the love of a wonderful man she had met years before playing a game she enjoyed – the card game! She wore her dress when she married Bob on May 8, 2010. The memories of that day are ones she shares with students as she informs them about organ donation and encourages them to share their decision with loved ones.

Lisa continues to inspire others, especially those waiting for a transplant. She understands their dark and sad days but she also understands the need to share hope, encourage others and the pleasure of getting back in the game. As they say at the poker table, "A Big Hand for the Little Lady!"



Lisa and Bob Zimmerer

## PROMOTING DONATION THROUGH SOCIAL MEDIA

#### **Facebook**

n May 1, 2012, Facebook announced the addition of a new tool under "Life Events," which allows individuals to choose "Health and Wellness" and then "Organ Donor." They can then select the date they registered their decision as an organ donor and share their story about why they chose to be a donor.

If a person is not registered, the new tool provides a link to their state's registry to record their donor designation. Finally, the new tool gives users the ability to share their decision as a public decision (all Facebook friends) or as a private decision (selected individuals).

The Facebook initiative increased on-line registrations in Missouri consistently during the first two-week period with a total of 751 individuals registering their donor decision. The first two days in week one documented the highest level of on-line registration: 344 (day one) and 220 (day two) registrations. Individuals registering their decision in Missouri's Donor Registry System can choose Facebook as an option for how they learned about the registry. To date, data is insufficient to determine if this is a primary avenue to the on-line registration feature.

The DHSS also has a Facebook page and published four posts about organ and tissue donation during National Donate Life Month (April). Donor and recipient families, registrants and people passionate about or who want to learn more about organ and tissue donation can stay connected at www.facebook.com/DonateLifeMO.

#### **Twitter**

The Organ and Tissue Donation Program and Registry utilized the department's Twitter account and issued 13 tweets during Donate Life Month (April). Program staff plans to expand beyond Donate Life Month and include tweets during National Hispanic Awareness Month, Donor Sabbath, etc. Follow us on Twitter at http://twitter.com/HealthyLivingMo to receive these tweets and other fact-filled, educational health messages.

Your commitment to organ, eye & tissue donation will NOT interfere with your medical care. First priority is to save your life. #organdonor

### FINANCIAL SUMMARY

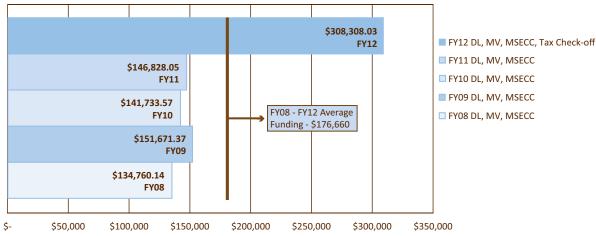
#### **Registry Summary**

Revenues more than doubled during FY12. Many factors contributed to the large increase including collaborative educational and recognition efforts by the MTS, MTN, DMV, and the DHSS; an increase in Missouri State Employee Charitable Campaign contributions; and the new Missouri Income Tax Check-off box option that began with income tax returns filed for 2011. The average annual revenue for the most recent five-year cycle was \$176,660. Expenses were kept to a minimum for FY12.

#### **Statement of Activities**

Fiscal years (FY) ending June 30, 2011 ar	nd June 30, 2012	
<b>Revenue</b> Department of Revenue contributions	<b>FY11</b> 142,949	<b>FY12</b> 296,681
Direct contributions/specialty plate	3,031	1,645
State Employee Charitable Campaign	848	1,208
Missouri Income Tax Check-off	0	8,774
Revenue Subtotal	\$146,828	\$308,308
Expense		
Registry	24,104	24,506
Educational initiatives/annual report	1,705	1,653
Personnel services/leave pay	70,248	65,068
Staff benefits (fringe benefits)	35,855	31,708
Administrative overhead		
- Indirect costs	24,191	22,839
- Network allocation	3,203	2,749
<ul> <li>Program supplies and expenses</li> </ul>	785	2,375
Network Adjustment	772	(981)
Indirect Adjustment	8,132	2,375
Expense Subtotal	\$168,995	\$152,292
Change in Net Assests		
- Beginning Fund Cash Balance	80,931	58,764
- Income	146,828	308,308
- Expenditures	-168,995	-152,292
Fund Cash Balance	\$58,764	\$214,780

#### Contribution History, by Fiscal Year



DL = Driver License Donation MV = License Plate Donation MSECC = Missouri State Employee Charitable Campaign

## MISSOURI DONOR DESIGNATION REPORT CARD

Missouri has a team of partners that work together to save lives through registering donors into Missouri's Donor Registry System. The more individuals that register their decision, the greater the chance those waiting for a live-saving or life-enhancing procedure can be helped. "Increasing the number of designated donors requires the effort and commitment of everyone," says David Fleming, president and chief executive officer of Donate Life America. All data on these pages are subject to change due to future data submission or correction.

#### **Donor Designation Share (DDS)**

#### Residents age 18 and Older - Calendar Year 2011 - Minimum Standard 50 Percent

The total number of designated donors as a percentage of all state residents age 18 and over. Some states allow enrollment of minors and data percentages may be high. In addition long-standing registries may reflect a lower than actual expected percentage of enrollees. Missouri permits enrollment of minors and has a mature registry.

		Donor Designations	State Population		Registry Inception
	State		18+	DDS	Date
₩	Arkansas	1,250,626	2,227,505	56%	1997
ΔΦ	Illinois	5,001,684	9,771,132	51%	1992
$\triangle \blacktriangle$	lowa	1,570,964	2,327,354	67%	2002
ΔΦ	Kansas	736,115	2,147,316	34%	2002
	Kentucky	1,161,874	3,348,401	35%	2006
$\triangle \blacktriangle \diamondsuit$	Missouri	2,928,357	4,598,567	64%	1996
ΔΦ	Nebraska	669,015	1,382,576	48%	2003
♣△☼	Oklahoma	1,747,514	2,855,349	61%	2004
△☆	Tennessee	1,652,476	4,911,217	34%	2008

#### **Donor Designation Rate (DDR)**

#### Minimum Standard 50 Percent

The rate at which individuals join the state donor registry as a percentage of all driver's licenses and identification cards issued within a specific period of time.

	Donor	DLs & IDs Issued by		
	20			
	Designations	State		
State		DMVs	DDR	
Arkansas	No data			
Illinois	No data			
lowa	No data			
Kansas	No data			
Kentucky	340,791	1,002,327	34.0%	
Missouri	622,000	1,526,514	40.7%	
Nebraska	235,137	537,669	43.7%	
Oklahoma	No data			
Tennessee	610,301	1,818,644	33.6%	

Source: 2012 National Donor Designation Repor	t Card, Donate Live America
---	-----------------------------

Missouri Jan-Dec,	Donor	DLs & IDs Issued by	
2011	Designations	State DMVs	DDR
Quarter 1	135,331	339,407	39.9%
Quarter 2	159,339	392,135	40.6%
Quarter 3	174,131	425,828	40.9%
Quarter 4	153,199	369,144	41.5%

Source: 2012 National Donor Designation Report Card, Donate Life America and Missouri Donor Registry System

**Missouri Registered Donors**The following tables reflect total unique registrants at the close of each fiscal year, June 30.

#### Registered Donor Designations, by Fiscal Year

FY	# Registered	Increase/ Decrease
2009	2,441,345	0.98%
2010	2,722,140	11.50%
2011	2,853,794	4.84%
2012	3,004,025	5.26%

Source: Missouri Donor Registry System

#### Registered by Age, as of June 30,2012

Age	Number of Registrants 6/30/2012	2010 Census	Percent of State Population Registered
≤ 14	13,980	1,177,625	1.2%
15-17	159,680	247,811	64.4%
18-24	568,901	589,264	96.5%
25-34	591,225	775,467	76.2%
35-44	527,802	748,616	70.5%
45-54	514,765	888,572	57.9%
55-64	361,885	723,278	50.0%
≥ 65	255,941	838,294	30.5%
Total Registrants Total Population	2,994, 5,988,	50.0%	

Registrants-All Ages, End of FY12; State Population-All Ages, U.S. 2010 Census

Donor Registry Data does not include those who did not indicate county of residence, out-of-state, or

deceased and since removed.

Source: Missouri Donor Registry System and 2010 U.S. Census Data

#### Registry Transactions Processed, by Fiscal Year

FY	Remote	Online	Paper	D <mark>e</mark> pt. of Revenue	Vital Records	Total
2010	0	2,629	2,374	822,387	12,398	839,788
2011	7	2,639	4,319	786,809	19,122	812,896
2012	0	4,206	3,570	940,184	16,100	964,060

Source: Missouri Donor Registry System

#### Recovery Authorized by Registry, by Type Calendar Year 2011

			Percent
	Recovered		Recovered
	Donors		Donors
	Authorized by	Recovered	Authorized by
	Registry	Donors	Registry
Organ Donors	118	238	49.6%
Tissue Donors	559	1,065	52.5%
Eye/Cornea Dono	ors 593	1,369	43.3%

Source: Missouri Donor Designation Dashboard; data supplied by organ and tissue procurement agencies with Missouri as the service area

## REPORT CARD CONT.

#### Missouri Registrants Ever Waiting by Age, by Fiscal Year

Age	FY09	FY10	FY11	FY12
<1	24	25	14	22
1-5	20	22	20	19
6-10	15	13	27	18
11-17	42	31	43	29
18-34	324	328	298	281
35-49	644	614	601	608
50-64	891	899	962	979
65+	260	319	317	354
Total	2,220	2,251	2,282	2,310

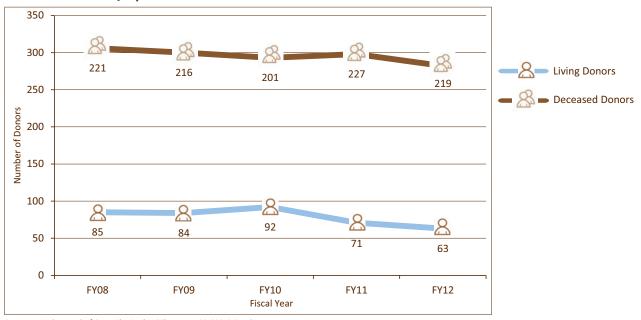
Note: Number of registrants ever on wait list for a transplant by age, by fiscal year where the candidates home state is Missouri. Candidate age is at the time of listing. Registrtions may be counted in multiple rows for "Date Ever Listed." Source: United Network of Organ Sharing (UNOS) Request 20120919-2

#### Missouri Deceased and Living Donors, by Age, by Fiscal Year

		<1	1-5	6-10	11-17	18-34	35-49	50-64	≥ 65
FY10	Living	0	0	0	0	33	30	26	3
	Deceased	1	11	4	10	59	53	41	22
FY11	Living	0	0	0	0	19	33	18	1
	Deceased	5	7	1	10	72	41	73	18
FY12	Living	0	0	0	1	13	25	22	2
	Deceased	7	3	1	12	56	65	58	17

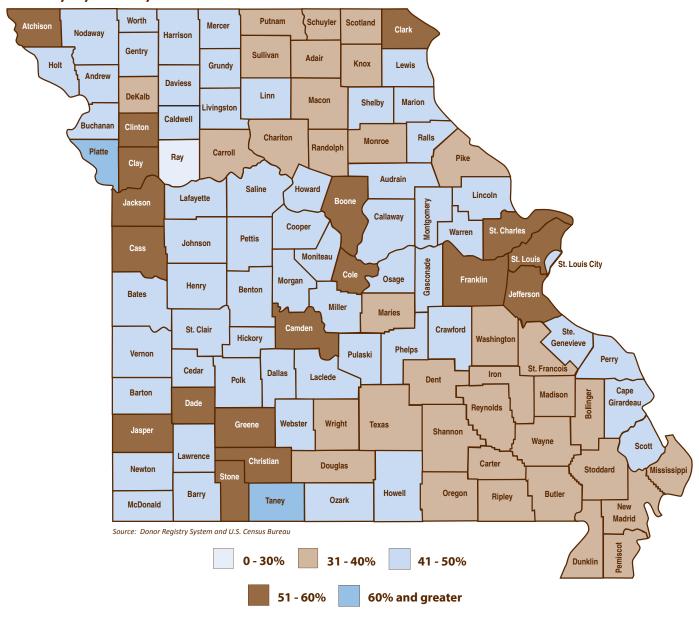
Source: United Network of Organ Sharing (UNOS) Requests 20120919-3 and -5

#### Missouri Donors, by Fiscal Year



Source: United Network of Organ Sharing (UNOS) Requests 20120919-3 and -5

#### **County by County**

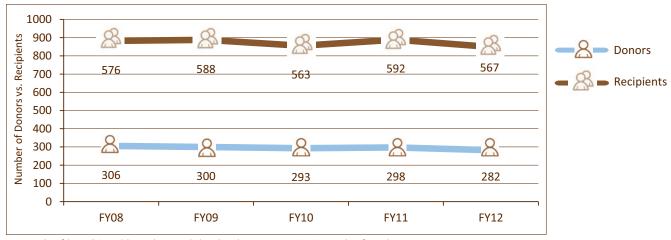


#### Registry Breakdown by County

The map shows the percent of county population registered as organ, eye and tissue donors for the period ending June 30, 2012.

## REPORT CARD CONT.

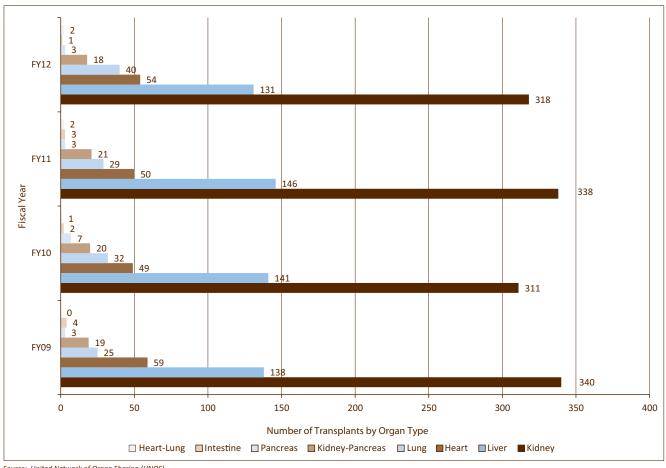
#### Missouri Donors vs. Transplants Performed, by Fiscal Year



Note: Number of donors, living and deceased, recovered where donor home state was Missouri vs. number of transplants performed where recipeint home state was Missouri.

Source: United Network of Organ Sharing (UNOS) Requests 20120919-3, -4 and -5

#### Missouri Transplants Performed, by Organ Type, by Fiscal Year



Source: United Network of Organ Sharing (UNOS)



Local driver license offices in Missouri are responsible for 98 percent of all registry enrollments and collect voluntary contributions that support Registry operations and education efforts. The average enrollment goal for each office in fiscal year 2012 (FY12) was 40 percent. Ninety-one offices met or exceeded this goal with several others very close! The average contribution goal for FY12 was ten percent with 52 offices meeting this goal. The goals will remain the same for FY13. Reports for each local license office in Missouri are available at www.health.mo.gov/organdonor, click on the "Reports" tab.

#### Quarterly Awards—FY12

Each quarter, local license offices that have the highest percent of registrations and collected the most contributions per transactions are recognized with a certificate. The following offices were recognized in FY12.

#### 1st Quarter

## Registrations Camdenton, Des Peres and Lee's Summit Contributions

Lamar, Des Peres and

Joplin

#### 2nd Quarter

## Registrations Platte City, Des Peres and Lee's Summit Contributions Lamar, Des Peres and Joplin

#### 3rd Quarter

## Registrations Platte City, West County and Lee's Summit Contributions Pineville, Des Peres and Joplin

#### 4th Quarter

Registrations
Platte City, Liberty
and Lee's Summit
Contributions
Pineville, Des Peres
and Joplin

#### Yearly

Registrations
Platte City, Lee's
Summit, Des Peres
and West County
Contributions

#### Contributions Fayette, Lamar, Des Peres and Joplin

#### Change Awards—FY12

Compared to FY11, the following license offices showed the highest percent of change for enrollment and contributions in FY12. A full report showing the percent of change for enrollment by office is available on the back inside cover. These offices received certificates in recognition of their efforts.

#### 

Contributions								
Aurora, Lawrence County	24%							
Bridgeton, St. Louis County	21%							
Warsaw, Benton County								
Des Peres, St. Louis County	13%							
Nevada, Vernon County								
Grandview, Jackson County	13%							
Carthage, Jasper County								
Gallatin, Davies County								
Kingston, Caldwell County								
Unionville, Putnam County								
Pineville, McDonald County								
,								

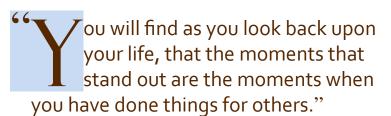
## LICENSE OFFICES SHOWING THEIR SUPPORT



The MTS promoted Minority Donor Awareness Day in August at the license office in Florissant, Mo. Fifty-eight people signed up to be organ, eye and tissue donors and an additional 100 learned more about organ and tissue donation.

Local driver license offices stepped up to the MTN challenge to Show Me Your Heart. Featured here are photos submitted by Belton, Carthage, Chillicothe, Lees Summit, Liberty, Monett, North Kansas City, Olivette, St. Joseph and Sugar Creek local license office personnel.

Reports for each local driver license office are available at www.health.mo.gov/organdonor.



- Source Unknown

#### MISSOURI REGISTRY PARTICIPATION

COUNTY/OFFICE NAME	FY12	% of Change	COUNTY/OFFICE NAME	FY12	% of Change	COUNTY/OFFICE NAME	FY12	% of Change	COUNTY/OFFICE NAME	FY12	% of Change
ADAIR			DENT			MACON			SCOTT		_
Kirksville	32%	0	Salem	35%	0	Macon	33%	+3	ChaffeeSikeston		-2 +1
ANDREW Savannah	41%	0	DOUGLAS Ava	34%	0	MADISON Fredericktown	36%	+1	SHANNON		
ATCHISON			DUNKLIN			MARIES			Eminence	31%	+1
Rock Port	46%	+3	Kennett			Vienna	35%	-4	SHELBY	4.407	. 0
AUDRAIN			Malden	25%	+1	MARION			Shelbina	44%	+3
Mexico Vandalia	38% 39%	+1 -4	FRANKLIN Pacific	50%	+4	Hannibal Palmyra		0 -3	ST CHARLES Harvester	51%	0
BARRY			St. ClairSullivan			MCDONALD			O'Fallon St. Charles		-1 +2
Cassville			Union	42%	-1	Pineville	39%	0	Wentzville		0
Monett	37%	+2	Washington	48%	0	MERCER	200/	0	ST CLAIR		
BARTON Lamar	42%	0	GASCONADE Hermann	46%	+2	Princeton	39%	0	Osceola	43%	+4
BATES			Owensville	33%	-1	MILLER Eldon	43%	+1	ST FRANCOIS Bonne Terre	37%	+2
Butler	43%	+3	GENTRY			MISSISSIPPI			Farmington		
BENTON	440/	0	Stanberry	46%	+1	Charleston	32%	-1	STLOUIS		
Warsaw	41%	-3	GREENE Glenstone	49%	+2	MONITEAU		_	AfftonBridgeton		+2 +1
BOLLINGER Marble Hill	31%	0	Republic	48%	-1	California	38%	+5	Chesterfield	52%	+2
BOONE			South Fremont Springfield			MONROE Monroe City	44%	0	Clayton Creve Coeur	52% 49%	+1 +4
Columbia	52%	+2	GRUNDY			Paris			Deer Creek	48%	+5
BUCHANAN			Trenton	34%	-2	MONTGOMERY			Des Peres Ferguson	25%	-2 0
St. Joseph	25%	+1	HARRISON			Montgomery City	43%	+5	Florissant North County		+3 +2
BUTLER Poplar Bluff	220/	+1	Bethany	39%	+3	MORGAN Versailles	260/	-1	Oakville	42%	0
	33 /0	TI	HENRY Clinton	200/	+1		30 /6	-1	Olivette Overland		
CALDWELL Kingston	48%	+6		30 /0	ŦI	NEW MADRID New Madrid	22%	-1	South County	42%	0
CALLAWAY			HICKORY Hermitage	37%	-1	NEWTON			West County	54%	+1
Fulton	34%	+4	HOLT			Neosho	40%	+1	ST LOUIS CITY  AAA St. Louis	36%	-2
CAMDEN			Mound City	44%	-4	NODAWAY			North Kingshighway	11%	-1
Camdenton	52%	0	HOWARD			Maryville	51%	+1	South Kingshighway St. Louis City Hall	33%	+3 +5
CAPE GIRARDEAU Cape Girardeau	44%	0	Fayette	46%	+1	OREGON Alton	29%	-1	STE GENEVIEVE		
Jackson	39%	+5	HOWELL Mountain View	34%	+6	Thayer		-1	Ste. Genevieve	49%	+2
CARROLL			West Plains	36%	+1	OSAGE			STODDARD		
Carrollton	37%	+2	Willow Springs	36%	-1	Linn	44%	+4	Dexter	30%	+1
CARTER Van Buren	31%	0	IRON Ironton	30%	+3	OZARK Gainesville	40%	0	STONE Crane	37%	+3
CASS	70	O	Viburnum			PEMISCOT		Ü	Lakeview/Branson West	47%	+2
Belton	51%	+3	JACKSON .	400/		Caruthersville	30%	-1	SULLIVAN		
Harrisonville	47%	+1	Blue SpringsGrandview			PERRY			Milan	32%	+1
CEDAR Stockton	32%	+4	IndependenceKansas City	38%	+8	Perryville	42%	0	TANEY Branson	48%	0
CHARITON	02 /0	14	Lee's Summit	55%	0	PETTIS Sedalia	420/	+2	Forsyth		
Keytesville	33%	+1	Raytown Sugar Creek	38%	-1 +5		4270	+2	TEXAS		
CHRISTIAN			JASPER			PHELPS Rolla	43%	+1	Cabool Houston		+1 0
Nixa			Carthage	42%	-3	PIKE			Licking		-1
Ozark	50 /6	74	Joplin Sarcoxie	46%	+2 +4	Bowling Green		0	VERNON		_
CLARK Kahoka	47%	+2	JEFFERSON			Louisiana	34%	-1	Nevada	47%	+5
CLAY			Arnold			PLATTE Parkville	50%	-1	WARREN Warrenton	39%	+2
Excelsior Springs			De Soto High Ridge			Platte City	56%	+4	WASHINGTON		12
Gladstone Liberty	53%	-2	Imperial Office	46%	+2	POLK	000/		Potosi	32%	0
North Kansas City	46%	+5	Twin City	46%	+2	Bolivar	38%	+1	WAYNE		
CLINTON Cameron	170/	+3	JOHNSON Warrensburg	46%	+4	PULASKI Waynesville	47%	0	Greenville	30%	0
Plattsburg			KNOX			PUTNAM		_	WEBSTER Marshfield	200/	-3
COLE			Edina	37%	0	Unionville	36%	+1		39%	-3
Jefferson City Jefferson City Mail In	47%	0 -1	LACLEDE			RALLS			WORTH Grant City	35%	+1
Jefferson City Mini Branch			Lebanon	419	6 0	New London	37%	0	WRIGHT		
COOPER			LAFAYETTE Lexington	38%	-1	RANDOLPH Moberly	43%	0	Hartville		
Boonville	42%	-1	LAWRENCE	00 /0		*	7070	Ü	Mountain Grove	21%	-1
CRAWFORD	200/		Aurora	38%	-1	RAY Richmond	39%	-1			
Cuba Steelville			Mount Vernon	47%	+1	REYNOLDS					
DADE			LEWIS Monticello	120/	0	Ellington	23%	+2	*Registry participation is for J	uly 2011 to	)
Greenfield	41%	+6		43%	U	RIPLEY	0501		June 2012 and is based on p	ercent of	
DALLAS	0001	^	LINCOLN Elsberry	36%	0	Doniphan	25%	+1	total transactions responding being placed on the registry.		
Buffalo	33%	0	Troy			SALINE Marshall	37%	0	agent changed during FY11,		t
DAVIESS Gallatin	36%	-8	LINN	2001	.0	SCOTLAND		·	may be altered. "Percent of C	hange"	
DEKALB	. 2070	_	Brookfield	39%	+2	Memphis	34%	0	refers to change from previous year. Data is subject to change		n
Maysville	47%	0	LIVINGSTON Chillicothe	42%	0				future data submission or cor		• •

